AMCHP Annual Conference, 2010

Moving Ahead Together:

Celebrating the Legacy, Shaping the Future of Maternal and Child Health

The Nuts and Bolts of Building Community-Based Service Systems for CYSHCN

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DIANA: All right. Eileen I'm going to let you begin with step one.

EILEEN FORLENZA: Okay. So step one again was looking at what is role and the value of a public health system? And that is again around especially with the framework that we have with the MCH pyramid are we truly, truly working at the level of empowerment for the community, building systems that are sustainable and workable for a very long time? Again to echo what Anna said, I lived in an area that I didn't feel like I was part of the club, to use her words and that is really about I felt like as a mom I was a single parent I did not really get that invitation if you will of which door was I to walk in and if only the system would have been more broadly disseminated how much sooner might I have been able to access the system? So in looking at the MCH pyramid and my role as a parent on this team is to always bring it back to what 's it like for the families? And so that's why I'll continue to go back and I don't mean to sound critical, but rather I will be analytical from a family perspective and so I just want to give that awareness that my partnership with the health department has been nothing but positive. And I have

always committed to stand on behalf of the family role and to analyze it from a business model and from a family model. So I just want to make sure you know that.

So again looking back at the values of helping families with a sustainable model, moving down the pyramid was important. It was actually for those of you who are parents in the room, it was actually one of my first years here as an AMCHP scholar and I was looking at our Colorado profile that document that AMCHP puts out. And we had a what 2 ½ million dollar budget for children with special health care needs program and when it said a number of children served, it was like 7000. I'm like 7000 people for 2 ½ million dollars? I don't think that's a very smart business model. And I as a parent, as a community member, as a tax payer as we all are didn't feel like I wanted to take that piece of paper to my capital hill visit that was happening on the next day and so I gently tucked that into my bag and came up with my own way that I would explain it to my legislator up on the hill and then when I went back to the health department I said we've got to work on these numbers because I really don't believe that we're only serving 7000 people for 2 ½ million dollars. I know that who we are serving is our broad population of children with special health care needs and in our state it's 15% of the population birth zero to 21 which equated to about 255,000 kids. And that, those numbers work a lot better for our legislators, our elected officials in general. So that's where that came from. Again it was the 80/20 model. We were spending on direct services, 80% of our budget, 20% of the families, again not something that would be sustainable and truly not the idea of a true public health model. Part of the value again with having parents as equal partners often times I hear and understand that those of us

who work at the…and because I wear many hats, I can understand the role of the state or the provider saying I just don't know how to work with families. We talk about having parents as partners but how do we do that? And I say well let's just dig in and let's try. And often the response is but the families that we work with may not understand how systems work. And so how do we begin to partner with families when we kind of speak a different language. I'm like then change the language. We can do this. So having that commitment in your very first step, I cannot express that enough. That understanding that families are human capital for your program. Do you understand what families bring to it? And as consumers, as the end user, whatever kind of name you want to call it; families are key partners in this process of moving down the pyramid. Families as equal partners are a big value we have to stick with. And moving away from this idea of servicing families that we provide services to, we provide services for, again this is a WIF model, this is a partnership. I know we've heard that over and over again but I just want to express it at this level of systems change for your program working with families is equally important as it is working on a care plan in a clinical intervention. And that's the piece that you learn through this is that families are part of your change process. Families, youth leaders who might have access to as well are also key partners. So keeping that in mind is a critical piece. As a…again as a family member who was accessing services, when I moved into the health department as a staff person I obviously was itching to get back out and wanted to do work in the community and it just wasn't set up that way. Oh we have reports and we have meetings and you have a meeting from 9 to 11 and another one from 2 to 4. I'm like how do you connect with families if you're never out in the community? So my mantra at the health department

was I am determined to keep the public in public health. And that's one of the mantra's that will help you, too, as you again change your system and always keep connected with the public with whom you're working and understanding that keeping a pulse on the community, keeping a pulse on the strengths, all families, all patients, all consumers, whatever word you want to use, will bring value to your process. And you have to buy into that very early on. And if you need help understanding how that happens I'm more than happy to talk with you about that further outside of this because I know that often in this very first step that can be one of the very first barriers to overcome.

DIANA: Thank you, Eileen.

UNKNOWN SPEAKER: Both Eileen and Anna emphasized that point of feeling as family leaders they weren't kind of part of the club. I'm wondering how that resonates with the family leaders here that we've got. Can you relate or…different perspectives? What do you think? I see someone nodding?

UNKNOWN SPEAKER: Was that me nodding?

UNKNOWN SPEAKER: Yeah. Yeah, you with the glasses, yeah.

UNKNOWN SPEAKER: I mean I agree too for a while I have felt it has been hard to understand what part of your club we can belong to and that educational tool takes a

while and requires you to connect with the right people to understand that language in the club.

UNKNOWN SPEAKER: Right and so does that mean that services are organized? So you at least can use them easily?

UNKNOWN SPEAKER: Yeah, I don't know. I mean I'm learning as I go but you know I think the eligibility pieces are (Inaudible)...

UNKNOWN SPEAKER: What state are you from?

UNKNOWN SPEAKER: Massachusetts.

UNKNOWN SPEAKER: Okay, thank you, yes.

UNKNOWN SPEAKER: We often find that our families don't know that the club exists.

UNKNOWN SPEAKER: : Right.

UNKNOWN SPEAKER: …find out because I'm a parent (Inaudible)...

EILEEN FORLENZA:: And to expand on both of those comments you can figure your situation out and it can change on a dime with changes in the system, so just when you

do get into the club, the club might change. Yeah, they change the eligibility requirements for the club.

UNKNOWN SPEAKER: For some reason I had that Woody Allen quote and I'll paraphrase, it goes something like I don't really want to be a member of any club that would have me as a member. Okay, yes.

UNKNOWN SPEAKER: (Inaudible)... foster care…(Inaudible)...

DIANA: Okay, great, thank you. I'm going to quickly take a look here. Eileen you had a couple here so I don't know if this was the analogy that I think that Anna…

EILEEN FORLENZA: That was just again through that process I was driving by Mile High Stadium in Denver and I went now that holds like 70,000 people and like Anna said if we fill that up like four or five times that would be the children with special health care needs in our state and then multiply that with siblings and the mom and dad and the families. So it was just a visual that helped me understand how much time this was going to take and of the evolution in general of how much we had to change.

UNKNOWN SPEAKER: And Eileen I don't know if you want to quickly…you hit on the keeping public in public health…there were some other points here I don't know you may have already discussed them.

UNKNOWN SPEAKER: I think one of the key resources is we use this book a lot. “Managing Transitions” by William Bridges. I would recommend this. I still write in it and have tabs so I’m not going to share it with you but I just…I mean like I won’t give it to you today, but if you want to browse through it I think it’s really helpful. I think it’s really important to have something that you go back to to help you stay grounded. You know something and this seemed to work for all of us so I’d recommend this book.

DIANA: So I’m going to let Harper talk about then as they work through this step one of inspiring a vision in mission what they did.

HARPER RANDALL: I want to backtrack just one second if I could just to say a couple things about this morning collaborative experience as we were plodding through our timelines can you imagine having these people on the phone with you almost monthly cheering you on, offering you support, giving you fresh ideas and encouragement so the learning collaborative it really…it made it…it took out the rocks in my river. It sort of smoothed out the water and it was just a fantastic experience and it continues to be. We still keep in touch and update so with Diane’s leadership it’s been great. And also the other frustration…the frustrating part for this presentation is we obviously are so excited about the process and all of the details but we’ve been told we can’t tell you them all right of now. So we’re all open for questions. There’s so much more we wanted to talk about but in the interest of time, we couldn’t. And then this book transition thirdly it was so key for my people as we were going through our people as we were going through this process to say it’s okay to have doubt and here look, this is typical as you’re going

through transition to be uncertain and to feel doubt and frustrated because look this wonderful guy has written and there's a diagram of it. And it was a nice thing for them to settle into and helped them a lot. So I support that. So the big challenge that we had was everyone in our bureau wasn't sharing my vision. The were…what we do feels so good and we're getting kudos for it and you're going to tell us we have to change and we're not going to get that anymore? But everybody says we need to keep doing it. So it was really getting everybody, the stakeholders within our bureau our work group on board and comfortable with our vision and so re-visiting that vision and mission statement was just central to our ability to move forward. So I'd been around for about a year thinking okay, all right, let's look at that vision. And I said where is our vision? And we didn't have one. So everyone was really excited about creating one and we came up with a very nice one. Utah Children and Youth with Special Health Care Needs and Their Families will have enhanced help and quality of life. And we were happy with that….

UNKNOWN SPEAKER: …and here it is the new vision statement.

HARPER RANDALL: …and then we moved on to our vision…mission statement and we found it to be cumbersome and wordy. It sort of seemed dark, reduced, (Inaudible)... death,

UNKNOWN SPEAKER: A bit of a downer…

HARPER RANDALL: Yeah. And it was also a false promise. We weren't assuring anything. I mean in particularly in this time when we're looking at cutbacks we couldn't assure all of this, so we worked together with all of the people that were on this team and said what do we really want to do? We want to enable, we want to facilitate. We want to be brokers. We want to help communities support their needs and that really got worked into the mission statement and without that process it would be a lot more abstract I think and harder to get your hand around so we ended up with to facilitate access to comprehensive community-based coordinated, culturally effective, and high quality health care and related services for Utah's children and youth with special health care needs and their families. I would love it to be shorter but we couldn't agree to eliminate any of those words so that was a key for us.

DIANA: Thanks, Harper and what hits me with this is to facilitate access. It's not saying that their CSHCN program has to take it on and provide absolutely everything but their role being to facilitate that access. All right and now we're going to hear from Maine.

TONI WALL: And I would like to just say that it is a process and this book, too, has been wonderful to us. Cathy recommended this when we were out in Colorado. We all went over to Barnes and Nobles that evening and bought a copy and were reading it and going oh. Look at that, that's why people grieve and don't want to move forward. This process takes a lot of time. And moving from a direct service system to a population based takes time. And I think if Cathy was here she'd really talk about the grieving

process that your staff goes through. It's an incredible amount of time. Harper, I think, just touched on it. People felt something when they were able to talk to families and pay for medical services and to you know thank you…and parents would thank them on the phone for thank you, you were my only option left to pay for this and we didn't have any other doors to turn to. That's really a difficult feeling to have to think about that you're never going to have that feeling again. It was very difficult for me as the director to say we're moving away from providing that service, to looking at population base and providing care coordination and my staff would be like well, what does that mean? And it's…we sat down, we talked about a vision. A vision provides a place to go. It provides direction. It's a guiding principle and I think we started it in 2007. It took us a long time to come up with a vision. We too, didn't even have a vision so when I looked at that I said where's our vision? There was no vision. So I agree with Harper. There was…non existent and we did not know where we were headed. We invited Maine Parent Federation, Bev was part of that and other systems and stakeholders into our group and our vision we created was it's going to be a place where children and families and that's where we're headed. How we're going to get there is through developing community-based service systems for with special health needs. That's our mission statement. We, too had the culturally competent, the coordinated, the comprehensive, everything that was in there was in the mission statement and it got so wordy we all thought how are we ever going to remember this because a vision statement should be something that is short, a mission statement you should be able to repeat and everybody knows what it is. So we decided that we're going to create values. These are the reasons we get up in the morning and come to work. So we put all those great words into our values

statement and I just really want to read them off because we spent a lot of time looking at this. We value, our commitment, compassion, creativity, integrity, knowledge, professionalism in providing the best services. A trusting collaborative, partnership with families that respects their diversity and recognizes that they are the constant in a child's life. A family-centered, coordinated approach designed to promote the health development and well being of children and their families in medical homes that promote optimal health and family satisfaction. Those are our values. That's why we get up every morning and come to work, all of us. No matter if you're working for the birth defects program, the newborn hearing program, our partners in chronic care program, our Maine care members services program, that's what we strive to do every single day as our values. And it will be and we are striving for it's a place where children and families do come first. Do you want to say anything?

UNKNOWN SPEAKER: No, thank you. You know and what you said is very important. The bureau is also going back and looking at its vision, mission statement and we're even wordier because from our old one we had vision, mission, values, principles, philosophy so there are ways to work around all that stuff.

UNKNOWN SPEAKER: Which list are you working on, yeah, yeah; I'm sorry I just have Maine's values here that Toni was going through. I'm sorry they weren't in front of you at the time.

TONI WALL: Can I just add one thing?

UNKNOWN SPEAKER: Yes.

TONI WALL: There is a handout in the back that says Inspiring Leaders. These are the ten steps that we use to creating a vision. It's just a single pager, but it's really great. And Inspiring Leaders Set a Clear Vision in a direction.

UNKNOWN SPEAKER: Okay, thanks Toni. And so one of the things that's so critical there is if everyone has this sense of what it is we're working towards, that's what will guide you through this process. And it may be that the process for your state means you know what we're going to discontinue our specialty clinics and move to more of a care coordination model or like some states like Oklahoma it means we're going to look for partners who could help us set up these community-based services so we could be working towards achieving our vision. So I just want to emphasize the different strategies you'll hear about are what worked for those states. And everyone needs to come up with what's going to work for theirs. So now we're going to move on to step two and then we're going to give you a chance to have some discussion. Jack, are we good?